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ABSTRACT

This paper discusses different approaches used by researchers to acquire a comprehensive picture of what family life is like when one of the family members is handicapped. Researchers must determine the best time to get a "true" picture of what family life is like and must determine whether parents describe the true family situation or react to their perceptions of societal expectations. Researchers must also understand the different perspectives of family observers/participants (such as the handicapped individual, siblings, parents, sociologists, or psychoanalysts), in their descriptions of family life. The paper recommends that researchers turn to the great artists and learn by their experience to develop new ways to describe reality. Examples of different dimensions of a complex reality are presented, as captured by researchers, autobiographers, and fiction writers in various cultural and social contexts. (JDD)

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HOW DO WE GRASP "REALITY" IN RESEARCH ABOUT FAMILIES WITH HANDICAPPED CHILDREN - AND WHAT IS REALITY?

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The article discusses different approaches researchers have used in order to get a comprehensive picture of what family life is like when one of the family members is handicapped. It examines ways of defining and analyzing the situation, and how different research traditions have produced different images and new myths.
The boarder-line between science and art is discussed. Examples of how different dimensions of a complex reality has been captured by researchers, autobiographers and fiction writers in various cultural and social contexts is presented.

"One has to step aside and wonder".
Albert Einstein.

The researcher's dilemma

In a research project a couple of years ago (22) I interviewed parents who had put their severally mentally retarded children into an institution. The parents were between 35 and 85 year old. Their children between 6 and 57. The parents were extremely different if you looked at their background, their socio-economic standards, their personalities, their beliefs. Their children were all diagnosed as severally mentally retarded - but apart from that diagnose, they certainly did not have much else in common.

I was fascinated to notice how dispite all individual differences, the same worries and the same problems appeared. I believe it has something to do with the existential dimension or awareness that becomes part of any family who has a handicapped child and somehow transforms their values and attitudes. What certainly was most fascinating was to see how this dimension seemed to come through regardless of social standard, age, if they lived in the countryside, in a big city or in a small municipality.

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Still, I sometimes wondered how much of the truth I was told - if you believe that it is possible to get a "true" picture of what life is like when you have a severally mentally retarded child.

When for example would be the "truest" time to come and get such a picture? In the first difficult time when the parents struggle to come to terms with the new and unwanted situation, when they are deep down in a mental crisis and try to cope with feelings of resentment, anger and guilt? If you look at the research done about families with retarded children you will soon be aware of the fact that a majority of researchers have found this period most interesting (12, 24, 8, 7) probably for a varity of reasons.

Or should you wait until the first crisis has passed and the every-day life, the daily struggle takes over? There certainly is made far less here, and strangely enough, it seems to have made less impact politically. The focus of the research in this period is also different, and more concerned with practical problems.

Or should one - as I did - wait until the parents and their children do not live to-gether any more? How do parents look back upon their lives after they have put their children away? Will they paint their life to-gether in darker or lighter colour once their children are in an institution? Will they have a need to glorify the circumstances at home or will they have a psychological need in describing their family life to-gether as more problematic and unbearable than it really was, thus defending their decision to put the child away? When do we get the truest picture of what is like to live with a severally handicapped child?

When people look back upon their life, they will not tell about the crucial events exactly as they were once experienced, because they will be interpreted in light of later events and influenced by the ruling social values of the moment (22). According to oral historian Paul Thompson, the information provided by interview evidence of relatively recent events can be assumed to lie somewhere between the actual social behaviour and the social expectations or norms of the time (23).

"I am clumsy. I grind my teeth - but I am your child"

When for instance the British psychologist Charles Hannam (12) wrote about his experience as a father to a son with Down's syndrom, he was among the first to confess about his anger and his deception. He even told about his wish to kill his new-born son.

When he publishes his book about his and other families experiences, his son David is 8 years old. He then describes his present family life as fairly good. He is full of fighting spirit. Hannam also describes the siblings' affection for their mongoloid brother.

When David is 16, the Hannam's decide to put him into an institution. And in a poignant article "I am clumsy, I grind my teeth - but I am your son", Charles Hannam says that the brothers tend to ignore their older, mongolid brother and that they find it very hard to include him in any parts of their lives. He also says this: "A few evenings ago I was thinking again I could not stand his stupid face. Thank God he was going to the hospital for three months. If only they would keep him there for good. Then David held out his hand to me and we sat hand-in-hand and I realized that his face isn't stupid all the time, he can smile warmly and he only looks stupid when he is anxious, and I often make him anxious." He also sadly remarks: "What had we to show after 16 years? Just a wave of the hand, David standing by the window, and, it would seem, not caring all that much."

Of course you will get different answer not just depending on the individual family pattern but also on when you are studying the family - the same as you will get different answers if you ask a couple about their marriage during the honey-moon, after the first child is born or after the divorce.

Do parents tell the truth?

Another question that should be asked is of course: do parents tell the truth? The British sociologist Margaret Voysey (24) for example thinks that parents to mentally retarded children do not. She believes that families with handicapped children above all try to live up to what is expected of them - to function as the society wants them to do - as a normal family. Voysey sees the behaviour of such families as strategies to reach this goal. She speaks about different myths about families with retarded children, about "secular versions of the masochistic attitude", about the redefinition of good and evil and how the families try to find positive values of differentness. She even

interpretes the professionals' invasion of the families' private lives as "a further source of consolation as they share in the mysteries of medical science and make this evident to uninformed others."

I do not share Voysey's belief, and I do think one is wise to realize that there are different truths. The subjective description of the moment when the doctor gives the parents the diagnosis does most often not fit with the journals' description of the same event. But which description is the true one?

When I asked the old parents in my investigation what kind of advice they would give to-day to new parents, they said: "I would say: Do not grieve too much". And many of them also said: "It has given us more joy than sorrow." Should I not have believed them? I did. I do think that they called a spade a spade, and I think they were quite realistic about themselves and their children, not idealizing their part of the drama. Measured against their experiences and against the little support they had received from society and their own network, they were surprisingly normal. But I also think that parts of reality sometimes is not communicated for strategical reasons. The living conditions for many families with mentally retarded children, small and grown-up, have been so poor and so difficult that it has seemed unwise to communicate positive findings.

Through whose looking-glass?

The description of a family with handicapped children will vary, according to who the spectator is and through which looking-glass he or she is looking at the same family, if you are inside or outside, an observer or a participant, in which scientific tradition you are working in and so forth. Medical glasses see desease. Sociologists tend to see strategies and structures. Psychoanalysists see unfulfilled dreams and frustration.

Sociologists and psychoanalysts often believe that they do not have much in common. They work in different traditions, have different terminologies and worship different gods. But both tend not to believe what their informants say - they always look under the table-cloth to see what is hidden there. Even if the sociologists label this strategies and the psychoanalysts defenses, they are basically saying the same: never believe parents on their words!

If you look at a family with an austistic child through Bettelheims eyes (1), you will get a picture of symbiosis and cold, unloving mothers, if you borrow Skinner' (21), you get a different picture. Clara Clairborne Park (4), will give you still another. The problem with some research, especially if they are carried out at prestigious universities or clinics is that they might form decades of professionals - and through them also influence how families feel about themselves.

Families with handicapped children are vulnerable. They have to solve a lot of emotional and practical problems, they have to fight against prejudice and myths - and sometimes also against scientists.

How parents describe themselves

Do we get closer to a true picture of reality if we look at the families' own stories?

In the last decades there has appeared a new type of literature written by parents or by people with handicap. They have published their experiences in novels, poetry and autobiographies. Pearl Buck (2) was probably the first who wrote about her mentally handicapped daughter. Since then, many have followed in her foot-steps. And many who have started with their own experiences have continued to do research, thus enlarging the reference of what living with a handicapped family member is like (8, 12, 22).

Is there a pattern among those who write? There are more mothers than fathers among the authors. Many of them have autistic or mongoloid children. There are few books written by parents to children with social or emotional difficulties, and few with severally handicapped or grown-up children. Some of the books reminds the reader of H.C.Andersens fairy tale about the Ugly Duckling. Few stories are about the Ugly Duckling who remained so and never became swans. Few sisters and brothers write about their handicapped sibling (19). Is this because the disabled child did not present an overwhelming problem in their lives, or because they did not want to hurt their parents' or their siblings' feelings? We do not know for sure as also the research about siblings is scarce (16, 10, 18).

Another characteristics for parents who write about their children is

that they all belong to the middle class. Economically and socially they have been living on the sunny side of the street. The birth of a handicapped child transformed their lives. It forced them to look at the other side of the street and what they found was appalling.

What is the implications of this? Are the experiences of western, mostly white, well-to-do and well educated parents expressing universial experiences of the pain and joy of being a parent to a handicapped child? Can they speak on behalf of other parents who for different reasons have difficult to verbalize their feelings?

Ingstad and Sommerschild (14) found great differences in family coping even in such a homogenous country as Norway. The meaning the parents gave to the experience of getting a disabled child seemed to be related to their own subcultural background, their previous life experiences and their initial expectations for the child. The classical crisis reactions so often described in literature about parents and by parents fitted best with those parents who had an upper middle class background. They described the event as "a great tragedy". Those from less priviledged parts of the population often had previous experiences of meeting difficult life situations. They described the same event as "one of those things that happen in life". Ingstad and Sommerschild also found that there was a clear tendency for variance in the content of meaning between different districts of Norway. They interpreted this as an indication of subcultural differences in values, experiences and expectations related to coping and generated over generations. In the northern parts of Norway where life conditions are rough and expectations of success not very high the description of getting a handicappede child was "one of those things....", while in the more prosperous southern parts it was seen as "a great tragedy".

When Ingstad did a comparative study in Botswana (15) a couple of years later, the parents of Botswana clearly seemed to have different feelings and different explanations about getting a handicapped child than Norwegian parents. Feelings of quilt for instance, so often described as an universial and common reaction in Western literature, were rarely found in Botswana. The origin of the disability were either witchcraft/sorcery, ancesstors anger, break of taboo with pollution of blood as a consequence, or "God's will". Ingstad believes

this might be a possible explanation why feelings of guuilt were rarely found among these parents.

Researchers have seldom gone into cultural and ethnical differences, nor have they been eager to study families with handicapped children in the transcultural culture of poverty in their own surroundings.

"Don't let the media create a monster out of me"

When Hanna Green (19) wrote about her own experiences in "I never promised you a rose-garden", it made a tremendous impact. Lately, also a few severally handicapped people have written about themselves. I believe Nigel Hunt who had Down's syndrom was the first mentally retarded who published his diary in 1967 (13).

As a literaly deed, however, I think Joye Deacon's book (16) is outstanding. Joey Deacon had cerebral palsey, could not speak, had never gone to special school and lived with three others severally handicapped men in a unit in a big institution in England.
The only person who understands his sounds is Ernie, also severally handicapped. Through him, and together with two other handicapped friends, they manage to write his biography, a tremendous physical and mental effort that produced four to six lines a day. "Last year I told my friend Ernie: I will soon be 53. Half of my years were silent, half of them were not, thanks to you. You gave me the chance to speak to the outside world."
His schooling amounted to three months. "When I had finished school I stayed at home, and Mum used to put me outside the front door. She used to ask me how many cars that had passed by, and I answered by winking with my eyes. Mum understood that." When he is 6, his mother died, and he starts his carreer in hospitals and institutions. He stayed in contact with his family even if he does not visit them very often. Still, the different family members stand vividly as individuals before our eyes, Deacon's biography lacks aggressivity and bitterness. When he - after 18 years of Christmas celebration at the institution - is invited to spend a Christmas with his family, he is filled with joy and thankfulness - not with anger over the other 17 Christmas Days he spent at the institution.

A generation later the computer has changed the scene. Without it

Christopher Nolan (20), who recently received the Book of the Year Prize in 1987, would probably still have been captured in his own silence. Nolan is an artist and treats his experiences as a such. "Can I climb socially constructed barriers?", he asks. "Can I ask my family to back me when I know something more than they. I know the heinous sceptisism so kneaded down constantly in my busy, sad world. What can a crippled, speachless boy do? My handicap curtails my collective conscience, obliterates my voice, beckons rudiments of my smiles and damns my chances of being normal." He also writes: "Don't let the media create a monster out of me." Nolan is surrounded by a devoted family. Without them his achievments would not have been possible. Still, they remain as shadows in his book. Should or would we regard Nolan's ambivalent introspective account as a "truer" representation of a multiply handicapped persons feelings than Deacon's biography?

The written and the unwritten world

All literature, be it research or fiction, pretends to give an interpretation or a model of reality. The Italian authour Italo Calvino (3) says that he distinguishes between the written world which exists in literature and the unwritten world which surrounds us, our lives. In the unwritten world with its mixture of people, events, nature, smells, we often have difficult to find meaning and perspective. To write - or to research - is to organize and dominate reality. "I think", says Calvino, "that we always write about what we do not know with the secret hope that the unknown world shall get a chance to speak through us.

If we want to capture the reality of families with handicapped children, we must look for new ways of uniting these two worlds. It is a difficult task. Stepen Kew (16) who has done research about siblings to handicapped children, describes the researcher's dilemma like this:

"The still surface of the pool of our experience is broken by an ill wind: we feel disturbed. The delicate balance between security and separation, confidence and fear, dependance and vulnerability is suddenly upset: we are beset by catastrophe by the unexpected, the unknown, by forces of destruction against which we have insufficient power to fight: we feel at such times that the

steady balance of our lives has been disturbed. This is hardly the language of science, but it is precisely here that the mistake has crept in, for we are not in fact dealing with the language of science but with the subjective language of experience. When we try to objectify experience we find that the metaphors through which it speaks break down, the edges grow blurred and indistinct, their meaning drains away." (p.29)

In search for a multidimensial reality

How could we work to capture the unknown world of reality? I think one of the most important things for the scientist is to look for more MULTIDIMENSIONAL methods in design and analysis, and in communicating the data. A few examples.

In a Norwegian theses Haldorsen (11) studied families with muscular dystrophy. But he did not only interview the parents about the situation but also their teen-aged children. Two different, and partly also incompatible, pictures of the same family appeared.

This is the same technique that the social anthropologist Oscar Lewis (17) used in describing a Mexican slum family.The different family members' stories about crucial life events were at the same time both different and alike. And that is precisely why we feel that we get a "truer" picture of what their family life is like. And not just this particular family, but through them also an understanding of social class and of a whole society.

This is of course a technique writers always have used in order to present complex realities. Sometimes through imagnied correspondence between different characters or fictional diaries.

Sometimes the same effect is obtained by a constant change of times and settings. Sometimes, as in Lawrence Durrell's famous Alexandria Quartet (5) each book represents four people's different views of the same events.

In the Middle Age the same word was used about science and art - the Greek "techne" and the Latin "Art". There is not - and should not be - a strict boarderline between fiction and scientific literature. Scientist must realize that description and analysis sometimes loose

both in validity and reliability if they are forced into a strict and rigid academic pattern. The scientific language does not always capture reality. Sometimes we must be content just listening and wondering.

In our scientific training we should turn more to the great artists and learn by their experience the same way as we learn statistics and refined research design. We need new ways to describe reality! That means that we also have to break barriers in our own minds, and in doing so we must also be aware of that we might put our academic reputation at stoke. We must, at the same time more humbly and more bravely, look for new ways not only in describing our findings correctly and relevant but also in a language that transmits empathy, compassion and solidarity.

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